

## Huntington's Disease

### Questions to Help Determine Symptoms and Limitations

#### Cognitive Symptoms

1. When did you start experiencing symptoms of HD (even if you did not know they were HD related)?
2. What are your main symptoms of HD?
3. Do you have difficulty learning new things?
4. Are you able to read?
  - a. What kinds of things do you read?
  - b. How often do you read?
  - c. Do you think you would be able to read an entire novel, like a 200 page book?
  - d. Would you be able to listen to a book on tape?
5. Do you have problems with memory?
  - a. What is worse, short term or long term?
  - b. What kinds of problems have you experienced with your memory?
  - c. If you had multiple appointments in a given week would you be able to keep track of where you needed to be and when?
  - d. How do you keep track of places you need to be and things you need to do?
  - e. Does someone specific remind you, do you use a calendar?
  - f. What kinds of things do you need to be reminded to do?
6. How long can you concentrate at one time?
  - a. 30 minutes? 60 minutes? 2 hours?
7. Do you have trouble with motivation?
8. Do you have difficulty following instructions?
9. Are you able to finish what you started?
  - a. If you started a puzzle, would you be able to finish it?
10. Have you shown any signs of change in personality or mood?
  - a. Example?
  - b. Did you change from an outgoing person to a quiet person?
  - c. Do you any trouble with impulsivity?
11. Are you able to go out by yourself?
12. Would you be able to work at a job with people?
13. Anywhere you go on a regular basis?

## Physical Symptoms

1. When did you first start experiencing involuntary movements/chorea?
2. In what parts of your body do you experience chorea?
3. Describe your chorea/involuntary movements.
4. How is your balance and coordination?
  - a. Do you have any difficulties with stairs?
  - b. Do you have any difficulty walking?
  - c. Do you trip or fall? How often?
  - d. Are there specific things that trigger a fall?
  - e. Do you use an assistive device?
  - f. Has a doctor recommended an assistive device?
5. Does anything make it better? Worse?
6. Are you taking medication for your chorea?
7. Does the chorea in your hands and arms give you difficulty?
  - a. Do you drop things?
  - b. How often do you drop things?
  - c. What kinds of things do you drop?
  - d. Do you have trouble holding a knife and fork?
8. How long have you had trouble using your hands?
  - a. Are you able to tie tennis shoes?
  - b. Are you able to shave?
  - c. Are you able to write? Is your handwriting legible?
  - d. Do you think you would be able to write someone a letter?
9. Have you ever injured yourself because of your chorea?
  - a. Example?
10. Has your chorea impacted your ability to work?
11. Do you have any issues with choking?
  - a. Is there any food that you choke on or have difficulty eating?

### Activities of Daily Living

1. Do you need help with personal care?
2. What help do you need with personal care?
  - a. Do you have trouble getting dressed?
  - b. Do you need to sit down to put on pants?
  - c. Do you need help with buttons or zippers?
  - d. Do you need a shower stool or shower bar?
3. What chores are you able to complete now, without assistance?
  - a. Do you need help or reminders when completing chores?
  - b. Do you need to take breaks when completing chores?
  - c. Do you forget steps when completing chores?
  - d. How many chores can you complete in a day?
4. Are you able to cook for yourself?
  - a. What do you cook for yourself?
  - b. Do you prepare meals from scratch or do you prepare frozen/pre-made meals?
  - c. Any snacks you prepare for yourself?
  - d. Do you use the microwave?
  - e. Do you use the stove or oven?
  - f. Could you follow a recipe from start to finish?
5. Have your hobbies changed because of your HD?
  - a. What has changed?
  - b. What are your hobbies now?
6. Do you have good days and bad days?
  - a. Describe a good day.
  - b. Describe a bad day.
  - c. How many bad days do you have a month?